



The **MS** and Hispanic American Experience

CANDID ANSWERS TO FREQUENTLY ASKED QUESTIONS

IS MULTIPLE SCLEROSIS (MS) WIDESPREAD IN THE HISPANIC COMMUNITY?

Multiple sclerosis is underrecognized and underestimated in the Hispanic community; however, the number of those diagnosed is increasing in the United States.¹

Although fewer Latinx people have MS, it does not mean they are impacted less from the condition. Hispanic people have similar experiences living with MS as those from other parts of the world and other backgrounds. If you are affected by MS, it is essential to seek care and treatment.²

ARE THERE DIFFERENCES BETWEEN THOSE LIVING WITH MS IN THE UNITED STATES AND THOSE LIVING IN OTHER PARTS OF THE WORLD?

Yes.

While we know MS is more common in regions in the northern part of the world, such as the most northern states in the US and Canada, there are very few studies about MS from countries in Central or South America, making it difficult to understand the difference.

For example, some research shows that Hispanic people who have lived in the United States for a longer time, or those born here, may have a greater risk of developing MS and at an earlier age.³ Overall, the scientific community needs more research on why this may be and specifically, how Vitamin D deficiency and limited sun exposure can impact MS risk factors.⁴

IT SEEMS LIKE THERE IS THIS MINDSET THAT “HISPANICS DON’T GET MS.” IS THIS TRUE?

Unfortunately, some people can still have this mindset. When few people have a health condition, it is considered rare and can take longer to diagnose. The number of those diagnosed with MS in the US is increasing, and the mindset is changing. The medical community is always working to address stereotypes to provide the best care possible.⁵ More research helps to raise awareness.

If you have been diagnosed with MS and feel like your doctor is minimizing your diagnosis and not taking your symptoms seriously, there are a few things you can do.

- 1** Ask your doctor about your MS, what you may expect as time goes on and how you can work together—as provider and patient—to best manage your MS. Some people feel nervous to ask their doctors questions.

 Tip: Write your questions down beforehand and hand your doctor the question(s) if you think it might help take away some of the pressure.

- 2** If possible, find a new doctor who will listen to you and validate your symptoms and experiences. It is vital to have a good relationship with your doctor. It is okay to find a different doctor if you feel it is necessary.

- 3** Connect with other people who are going through similar situations. It can be beneficial to be involved in support groups for:

- moral support
- feeling validated
- learning about new doctors and how others advocate for themselves

WHAT DO I NEED TO KNOW AS A PERSON LIVING WITH MS IN THE UNITED STATES?

You can live a normal life with MS. It is important to understand the condition and find a doctor you can trust. Talk to them about the best ways to manage your symptoms and treatments.

Find your support network, and don't be afraid to ask your friends and family for help. Friends and family are often the first people you may seek support from, but remember that there are trained professionals that are there to help you too. There are also organizations, like the Multiple Sclerosis Association of America (MSAA), that have online resources to help.

- MSAA has an online peer-to-peer forum, My MSAA Community, which can be found here: healthunlocked.com/msaa
- Additional resources are available here: resources.mymsaa.org
- Stay involved with MSAA: mysaa.org



WHAT ARE HEALTH DISPARITIES, AND HOW CAN THEY IMPACT MY LIFE?

Health disparities are the differences people experience based on access or availability of services. Underserved populations may have a more difficult time getting to a doctor, paying for a doctor, or managing their MS due to challenging circumstances.⁶

Examples of challenging circumstances:



A doctor's office is only open 9-5, making it difficult to go when you are not at work



Health insurance is expensive and not covered by your employer, which means you will be less likely to receive care because you cannot afford it



Affordable housing may not include access to elevators or space to move around comfortably



You live far from your MS doctor and you do not have reliable transportation



Language may also be a barrier, but you do have the right to an interpreter at hospitals across the country

There are several MS organizations that can provide the information and resources that may help you navigate these issues as they come up.

MSAA is one organization and their Client Services team is available at (800) 532-7667, extension 154 or via email at MSquestions@mymsaa.org. A live Chat is also available at mymsaa.org/chat

WHY IS IT IMPORTANT FOR RESEARCH TO INCLUDE THE HISPANIC COMMUNITY WITH MS?

Research is one area where the Hispanic community living with MS is underrepresented compared to other groups:

- MS seems to be more severe in communities of color, such as in Black and Hispanic communities, but more research is needed to understand why.
- Doctors need more information on which treatments are best for specific populations.
- Magnetic resonance imaging (MRIs) possibly show differing results for Hispanics compared to whites, but because there is limited data, researchers are not sure of the differences.
- There needs to be a better understanding of the role of diet and exercise for those living with MS.⁷

Without research, new medications, procedures or a better understanding of how to manage MS would not be available.

HOW CAN I LEARN MORE ABOUT GETTING INVOLVED IN CLINICAL RESEARCH?

If you're interested in learning more about getting involved in research, you can consider visiting the below websites.

Websites:

- **MSAA**
mymsaa.org/clinicaltrials
- **Alliance for Research in Hispanic Multiples Sclerosis**
arhms.org
- **US National Library of Medicine**
ClinicalTrials.gov

"I was diagnosed over 30 years ago, and it took a long time— at least a few years — to receive an MS diagnosis. I was told 'Hispanics don't get MS,' but they do. I know I am not the only Latinx with MS, and I'm certainly not alone in my battle."



Sources

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